Parental views on special educational needs provision: cross-syndrome comparisons in Williams Syndrome, Down Syndrome, and Autism Spectrum Disorders

Jo Van Herwegen[1]

Maria Ashworth[1]

Olympia Palikara[2]

[1] Department of Psychology, Kingston University London

[2]School of Education, University of Roehampton

Address correspondence to:

Dr Jo Van Herwegen, Department of Psychology, Kingston University, Penrhyn Road

Kingston-Upon-Thames, KT1 2EE

Tel: +44 (0) 20 8547 2803

Email: J.vanherwegen@kingston.ac.uk

Abstract

Background: The current study examined parents' views about their child's educational provision for children with Williams syndrome (WS), Down syndrome (DS), and Autism Spectrum Disorders (ASD). Aims: This cross-syndrome comparison explored the specific and general difficulties that parents of children with neurodevelopmental disorders experience about their child's educational provision. Methods and procedures: Parents of children aged 4 to 18;11 years old, including 99 with WS, 88 with DS, and 82 with ASD completed a survey. Outcomes and Results: Children with DS were more likely to access mainstream settings and 1-to-1 support compared to those with WS and ASD. Parental satisfaction was lowest for those with ASD but all parents mentioned concerns about professionals' knowledge of how to support children with special educational needs and disabilities (SEND). There were also group differences for access to specialist support but overall access to occupational therapy and mental health was low. Conclusions and Implications: In contrast to previous studies, educational provision and satisfaction with educational provision are syndrome-specific. These results also highlight the need for training and raising awareness about the specific needs of children with neurodevelopmental disorders. In addition, our findings suggest improved communication between parents and the school is required about the type of support children with SEND are receiving.

What this paper adds?

This study is the first large cross-syndrome comparison to explore educational provision and special education needs support for children with Williams syndrome (WS), Down syndrome (DS), and Autism spectrum disorders (ASD) in the UK. Comparison of neurodevelopmental disorders that show overlapping and different phenotypes allow further insight into the specific and general difficulties that parents of children with Special

Educational Needs and Disabilities (SEND) experience in relation to their child's educational provision.

Keywords: Educational provision; Special Educational Needs and Disabilities (SEND) support; Williams syndrome; Down syndrome; Autism spectrum disorders

Highlights

- Educational placements, access to specialist support, and 1-to-1 support are syndrome specific.
- Parental satisfaction was lower for children with ASD compared to WS and DS
- Parents expressed concerns about professionals' awareness of the specific needs of children with neurodevelopmental disorders
- Access to specialist support is low, especially occupational therapy and mental health support.

1. Introduction

There has been an increasing interest in the parental views about their child's educational provision and support for children with Special Educational Needs and Disabilities (SEND). This interest has been sparked by three premises. First of all, it has been argued that parental involvement and satisfaction with the educational provision might benefit educational outcomes for children. Secondly, parental involvement and satisfaction may also be linked to the appropriateness of the child's educational provision. Finally, there has been an increased recognition of the parental rights in relation to their child's educational provision (see Lindsay, Ricketts, Peacey, Dockrell & Charman, 2016 for a discussion). Although a number of research studies have examined the parental views of children with SEND, there is a dearth of research on the parental views of children with neurodevelopmental disorders, especially those with rarer disorders such as Williams syndrome. In addition, conclusions from these studies have been hampered by the lack of appropriate control groups. The current study examined the views and experiences of parents with children with Williams syndrome (WS), Down syndrome (DS), and Autism spectrum disorder (ASD). Cross-syndrome comparisons of the experiences and difficulties related to educational provision allows examination of the syndrome specific challenges compared to the general difficulties that parents of children with SEND experience with regards to their child's educational provision. Further information about the difficulties and challenges that parents experience will allow improvements in educational provision to support better long-term outcomes for children with neurodevelopmental disorders.

Although there are large individual differences in all neurodevelopmental disorders (see Charman, 2015; Tsao & Kindelberger, 2009; Van Herwegen, Rundblad, Davelaar, & Annaz, 2011), children with neurodevelopmental disorders have been shown to have overlapping as well as distinctive cognitive and behavioural profiles. People with Williams

syndrome (WS), a rare genetic disorder that is caused by a genetic deletion on the long arm of chromosome 7 and affects about 1 in 20,000 live births, show an overall cognitive delay with general IQ scores between 42-68 (Martens, Wilson & Reutens, 2008). Moreover, people with WS have significant and complex difficulties including general cognitive delay, health and sensory issues, fine and gross motor problems, and anxiety. In addition, those with WS often show an uneven cognitive profile with better language, auditory memory, and face recognition abilities, in contrast to severe visuo-spatial and planning abilities (Martens et al., 2008). This cognitive profile contrasts with the short memory and language difficulties observed in individuals with Down Syndrome (DS), despite the fact that both developmental disorders have similar overall IQs (Silverman, 2007). Behaviourally individuals with WS show similar difficulties and sensory profiles to those with Autism Spectrum Disorders (ASD), including resistance to change, repetitive behaviours, and sensory needs, even though those with WS are generally highly sociable in contrast to those with ASD (Rodgers, Riby, Janes, Connolly & McConachie, 2012). In addition, both children with WS and ASD show higher levels of anxiety and mental health difficulties, in contrast to those with DS (Evans, Canavera, Kleinpeter, Maccubbin & Taga, 2005; Leyfer, Woodruff-Borden, Klein-Tasman, Fricke & Mervis, 2006). The varying overlapping strengths and difficulties in these disorders' phenotypes as well as the varying prevalence of the disorders, with WS being rare and DS and ASD being common developmental disorders, allow for useful cross-syndrome comparisons that can provide insight into the unique issues related to educational provision required to address the needs of these children.

Previous studies have shown that parents of different neurodevelopmental groups have different levels of satisfaction with the educational provision or placement for their child. For example, parents of children with Prader-Willi syndrome (PWS), another rare genetic disorder, have been found to be more dissatisfied than those with DS (Hodapp,

Freeman, & Kasari, 1998) and have a stronger desire for improved physical education services. In contrast, parents of children with WS wanted more in-class support as well as more musical instruction for their child, in contrast to those with DS and PWS (Fidler, Lawson, & Hodapp, 2003). Yet, a parental survey in the UK of parents of children with ASD found no differences between the ASD and non-ASD group for the type of educational placement, the progress the child was making in the school setting or how much the school setting was helping the child with difficulties (Parsons, Lewis, & Ellins, 2009). However, this study included a very mixed non-ASD control group and thus it was not clear how different the control group was from the ASD group in terms of cognitive and behavioural severity. Similarly, Lindsay and colleagues did not find any differences between the parental views of children with ASD and those with language impairments with respect to the child's educational progress, overall satisfaction with the school or the educational provision to meet the child's needs (Lindsay et al., 2016). Therefore, whether or not any differences between groups can be found, not surprisingly, depends on the phenotypes that are being compared.

In addition, it has been suggested that parental satisfaction is not necessarily related to the educational placement of the child, but rather to the type and amount of support that children receive within that placement (Starr, Foy, Cramer & Singh, 2006). For example, studies in the USA have shown that, although there were no differences between parents of children with WS (n= 21), DS (n= 21), and PWS (n=25) for overall placement satisfaction and number of hours of provision, there were differences in the desire for specialist support, with DS wanting increased speech and language therapy (SLT) support and those with WS desired more 1-to-1 support. In addition, those with DS reported more support from specialists in the classroom compared to those with WS (Fidler, Hodapp & Dykens, 2002).

In a recent study in the UK, Reilly, Senior, and Murtagh (2015) examined the views of parents (n=381) and teachers (n= 204) of children aged 4 to 19 years old with four

different neurodevelopmental disorders including Fragile X syndrome, WS, PWS, and Velo-Cardio-Facial syndrome (VCFS). The questionnaires assessed a variety of issues including the type of school placement, views on the needs of children, desired changes to current provision, and perceived teacher knowledge. They found that fewer of children with WS attended special schools and that fewer WS children had a Special Educational Needs (SEN) statement, a document that sets out the child's SEN and any additional help the child should receive, compared to the other rare syndromes. When they broke educational provision down by age, they found that most of the younger children attended mainstream and that this percentage decreased with more children attending specialist schooling by secondary school age. Finally, they asked parents about how knowledgeable they thought the staff were about their child's syndrome. Only 23% of parents of children with WS disagreed that staff knew about their child's syndrome, in contrast to 55% in VCFS but numbers differed depending on whether the child was in mainstream or special education (Reilly et al., 2015). Although this study has shown that educational provision and satisfaction with this provision is syndrome specific, all of the groups included children with relatively rare developmental disorders with very different cognitive and behavioural profiles.

1.1 Current study

In light of the lack of studies that have examined the parental views of children with neurodevelopmental disorders that have comparable cognitive and behavioural phenotypes, the current study surveyed the type of provision and support that children receive and the parental satisfaction with this provision and support across three different neurodevelopmental disorders: including WS, DS, and ASD.

Specifically, we compared across these three groups: the type of educational provision children attended, the proportion of children that have 1-to-1 support, as well as how this relates to the type of school setting and level children attended, and what kind of

specialist additional support (e.g., SLT, Occupational therapy (OT), etc.) children receive. For parental satisfaction, we evaluated overall satisfaction with the educational provision, the current level of 1-to-1 support, satisfaction with the current additional specialist support, and whether parents felt that school staff understood their child's needs. Seeing the cognitive overlap between WS and DS, it was hypothesised that they would attend similar placements and that placement satisfaction would be similar. However, due to the rarity of the disorder it was hypothesised that parental satisfaction of school staff knowledge in the WS group would be less compared to those children with more common neurodevelopmental disorders such as DS and ASD. With regards to the amount and satisfaction of specialist support, it was hypothesised that the type of specialist support received would match the cognitive and behavioural strengths and weaknesses of the neurodevelopmental disorders included and that satisfaction would be syndrome specific.

This study was part of a larger project that examined the impact of the new SEND framework for children with WS, DS, and ASD in England and Wales. This project engaged a range of methodologies, including a large parental survey and only the educational provision questions are reported in the current study.

2. Methods

2.1 Participants

Parents of children with WS, DS, and ASD aged 4;00 to 18;11 years old were invited to complete the online survey using a database of parents who had previously taken part in our research. We also recruited parents via a number of parental online support groups, including the Williams Syndrome Foundation UK, and social media campaigns. Thus, parents could have accessed the survey through a number of different routes.

2.2 Materials & Procedure

The survey was structured around 3 main themes and included: 1) type of educational provision, 2) amount of 1-to-1 support, 3) type of specialist support from external professionals. For each of these themes the parent was asked about current provision as well as their satisfaction with this provision. Question formats included multiple choice answers or Likert scales.

Parents were provided with detailed information about the project and provided written consent. The survey was anonymous and parents were not required to provide names. This project had received favourable opinion from the xxxx Ethics Committee.

2.3 Data analysis

Rating scales were analysed using non-parametric Kruskal-Wallis tests. Significant results were further analysed using non-parametric Mann-Whitney tests with adjusted p-values. Scalar data was compared across the three groups using one-way-ANOVA's and any significant results were further analysed using post-hoc Tukey HSD tests. Multiple choice questions were analysed using Chi-Square analyses and unstandardized residuals were used to identify the significant differences between the different categories.

3. Results

3.1. Background of the respondents and children/young people

The survey was completed by 99 parents of children with WS (52% girls), 88 of children with DS (46% girls) and 82 of the parents had a child with ASD (22% girls). A full description of the parents and their background can be found in Table 1 and background characteristics of the children and young people are provided in Table 2. Note that the number of participants per question throughout differs as completion of questions was optional.

The survey was in 99.2% cases completed by mothers. There were some differences between the groups for the children who had received a dual diagnosis, in that 53% of children with ASD had an additional diagnosis, in contrast to just 15% for children with WS and 22% of children with DS; $\chi(2) = 34.003$, $p < .001$. As can be seen in Table 1, there were no significant differences among parents in the three groups for Socio-Economic Status (SES) as measure by the highest level of educational qualification obtained by the mother; $\chi(12) = 18.521$, $p = .101$. In addition, participants in all three groups were recruited from across the UK.

Table 1. Background characteristics of the parent respondents (n= 269)

				Total actual responses	
	WS (n)	DS (n)	ASD (n)	n	%
Socio-economic status					
No formal qualification	1	3	1	5	2
Educated to O-levels	19	9	10	38	14
Educated to A-levels	7	1	2	10	4
Vocational	17	8	13	38	14
Graduate degree	23	22	28	73	27
Post-graduate degree	19	23	18	60	22
Other	1	5	2	8	3
Missing	12	18	8	38	14
Where living in the UK					
Scotland	1	2	0	3	1
Wales	0	2	0	2	1
Northern Ireland	0	0	0	0	0
South East	12	9	6	28	10
Greater London	9	9	9	27	10
South West	12	7	5	24	9
South	13	16	30	61	22
East Midlands	7	1	7	15	6
West Midlands	13	4	6	23	8
Yorkshire	10	9	2	21	8
North East	2	4	1	7	3
North West	9	6	6	21	8
Missing data	11	20	10	41	15

Note: missing data refers to 'no response'

Overall, there was a significant difference for age between the children with WS (mean = 123.36, SD = 50.52), DS (mean = 123.45, SD = 48.96), and ASD (mean = 149.59, SD= 45.45); $F(2, 267) = 8.116$, $p < .001$, $\eta^2_p = .059$. As can be seen in Table 2, there were a few differences between the groups for school age in that the WS sample included a larger proportion of preschool children compared to the other two groups, and the ASD group included a larger proportion of secondary school age children; $\chi(8) = 20.349$, $p = .009$. However, there were no differences between the WS and DS group for the number of children in primary and secondary school. These differences will be taken into account when interpreting the results in the discussion.

Table 2. Background characteristics of the children (n= 269)

				Total actual responses	
	WS (n)	DS (n)	ASD (n)	n	%
School Age					
Reception	17	6	5	28	10
Primary	55	52	35	142	53
Secondary	27	30	42	99	37
Missing	0	0	0	0	0
Type of current educational provision					
Mainstream	42	51	34	127	47
Mainstream with specialist provision	11	9	7	27	10
Specialist	46	27	28	101	37
Home-educated	0	1	9	10	4
Missing	0	0	4	4	2
1-to-1 support					
Yes	65	72	39	176	65
No	20	6	24	50	19
Missing	14	10	19	43	16

Additional formal support					
Yes	67	65	51	183	68
No	24	13	25	62	23
Missing	7	10	6	23	9

3.2. Educational provision of the children and young people

A comparison of the type of current educational provision attended by the participants showed that, whilst most of the children with WS attended specialist school (46%), a significantly larger proportion of children with DS (58%) attended mainstream education compared to those with WS and ASD. In the ASD group, there was a larger proportion of children that are educated at home (11%); $\chi(6) = 23.981$, $p < .001$ (see Table 2). However, further analysis of how these results are affected by school age show subtle differences. Whilst at primary school level, those with DS are more likely to attend mainstream compared to those with WS and ASD; $\chi(6) = 16.595$, $p = .011$, there are more children with ASD in mainstream school at secondary level compared to those with WS and DS; $\chi(6) = 20.142$, $p = .003$.

As can be seen in Table 2, there was a significant difference between the three groups about whether or not the children received some kind of 1-to-1 support; $\chi(2) = 18.854$, $p < .001$. More children in the DS group received 1-to-1 support compared to the WS group and the ASD group was least likely to receive 1-to-1 support. These group differences were still prevalent when the different types of current educational provision children attended were compared. For example, when comparing only those children who attend mainstream school settings, those with DS (98%) were still more likely to receive 1-to-1 support compared to those with WS (82.5%) and those with ASD (66.7%); $\chi(2) = 14.024$, $p = .001$. In addition, these differences were significant across the different school ages and those with DS are more likely to receive 1-to-1 support at primary; $\chi(2) = 11.081$, $p = .004$, as well as

secondary school level; $\chi(2) = 6.914$, $p = .032$. However, the difference between the WS and DS group is no longer significant at secondary school level.

There were no group differences in the proportion of children per group that received additional specialist support (including OT, SLT, Physio etc.); $\chi(2) = 6.683$, $p = .154$ and between 62-74% of children in each group received some form of additional specialist support (see Table 2). However as can be seen in Table 3, examination of the type of specialist support received differed significantly between groups. Interestingly, while two-thirds of children with DS have access to SLT, most children with WS and ASD do not; $\chi(2) = 18.726$, $p < .001$, despite the fact that speech and language difficulties have been well reported for all three neurodevelopmental disorders. There was no difference between the groups for OT support in that in all groups a limited number of children receive formal OT support; $\chi(2) = 1.081$, $p = .583$. Although the total number of children receiving physio therapy is very small, those with WS are more likely to receive it compared to the two other groups; $\chi(2) = 18.300$, $p < .001$[1]. Despite the fact that 93.4% of parents considered their child to have SEN needs (1% did not know and 3.8% did not answer the question), only about half of the children in each group received some form of specialist SEN support (Table 3). However, there are no differences between the three groups; $\chi(2) = 4.106$, $p = .128$. Finally, for all groups there were very few children who received any specialist support related to their mental health. Yet, children were ASD were slightly more likely to receive mental health support; $\chi(2) = 6.146$, $p = .046$) (see Table 3).

Table 3. Type of additional specialist support per group (n= 269)

				Total actual responses	
	WS (n)	DS (n)	ASD (n)	n	%
SLT support					

[1] As the WS group included a larger proportion of preschool children this analysis was repeated including only those children at primary school age and above and the result remained significant: $\chi(2) = 9.550$, $p = .008$ with children with WS being more likely to receive physiotherapy.

	Yes	40	55	25	120	45
	No	59	33	57	149	55
	Missing	0	0	0	0	0
OT support						
	Yes	22	23	16	61	23
	No	77	65	66	208	77
	Missing	0	0	0	0	0
Physio support						
	Yes	27	14	3	44	16
	No	72	74	79	225	84
	Missing	0	0	0	0	0
SEN support						
	Yes	45	53	42	140	52
	No	54	35	40	129	48
	Missing	0	0	0	0	0
Mental health support						
	Yes	5	4	11	20	7
	No	94	84	71	249	93
	Missing	0	0	0	0	0

3.3. Parental satisfaction with educational provision and support

As can be seen in Table 4 for the item "Satisfaction with 1-to-1 support", parents of children with ASD were less satisfied with the 1-to-1 support their child currently received and the overall support of the school, compared to the other two groups (p's < .01 for WS vs. ASD and DS vs. ASD) but there were no significant effects for the WS and DS group comparisons. Yet, there were no differences between the three groups for the satisfaction with the child's educational progress during the past academic year. Many parents in all three of the groups, but mainly in the ASD group, provided additional comments that staff '*do not get my child*' or '*do not understand the needs of my child*', as well as that staff were not trained enough, that there was a lack of consistency of 1-to-1 or high turn-over of the support staff, and that they wanted more 1-to-1 support.

Further examination of parental satisfaction with the support the educational setting provided revealed some further group differences (see Table 5). Parents of children with WS and DS were more likely to agree that the school met their child's SEND needs compared to those with ASD; $\chi 2$ (8) = 36.829, $p < .001$. In addition, despite the fact that children with WS and ASD have similar behavioural and emotional difficulties, parents of children with ASD were less likely to agree that the school could meet their child's social and emotional needs; $\chi 2$ (8) = 36.147, $p < .001$. Parents of children with ASD were also less likely to agree that the school were able to meet their child physical needs and this was in strong contrast to the higher agreement in the WS group; $\chi 2$ (8) = 20.489, $p = .009$. There were group differences for whether parents believed the school could meet their child's medical needs; $\chi 2$ (8) = 45.795, $p < .001$. Again, parents of children with ASD were less convinced that the school could cater for their child's medical needs, even though, despite being more frequent, the medical needs of children with ASD resemble those of the typical population (e.g., asthma, headaches and issues related to the digestive system) and are less complex compared to the medical needs of those with WS and DS whose medical needs may include cardio-vascular and renal difficulties. The high number of missing data reflects the fact that most children with ASD do not have any specific medical needs and thus parents rated the question as not relevant to their child. However, more worrying was the finding that a considerable proportion of parents of children with WS did not know whether the school provides for their child's medical needs at all. Finally, WS parents are more likely to say that the teachers know their child's strength than those with ASD; $\chi 2$ (2) = 18.378, $p = .001$. This finding is rather surprising seeing the fact that WS is quite rare, in contrast to ASD.

Table 4. Mean ratings (ranks) for group comparisons by question

	Mean rating (Rank) (df= 2)

	WS	DS	ASD	$\chi 2$ for Kruskal-Wallis test
Satisfaction with 1-to-1 support	3.25 (97.28)	3.25 (100.01)	2.81 (87.82)	$\chi(2) = 9.572$, $p = .008$
Satisfaction with child's educational progress	3.81 (142.49)	3.74 (138.01)	3.29 (122.73)	$\chi(2) = 3.266$, $p = .195$
Satisfaction with overall support	3.17 (100.94)	3.15 (96.77)	2.69 (72.57)	$\chi(2) = 11.234$, $p = .004$

Table 5. Satisfaction with educational setting support per group (n= 269)

				Total actual responses	
	WS (n)	DS (n)	ASD (n)	n	%
Do you feel that the school is good at meeting your child's special educational needs, for example in relation to his/her learning needs?					
Yes	62	48	26	136	50
No	5	5	22	32	12
Sometimes	26	29	26	81	30
Don't know	0	2	4	6	2
Missing	6	4	4	14	6
Do you feel that the school is good at meeting your child's social and emotional needs?					
Yes	57	42	23	122	45
No	10	8	29	47	17
Sometimes	26	30	22	78	29
Don't know	0	3	4	7	3
Missing	6	5	4	15	6
Do you feel that the school is good at meeting your child's physical needs?					
Yes	64	59	35	158	59
No	4	6	15	25	9
Sometimes	24	17	24	65	24
Don't know	1	2	4	7	3
Missing	6	4	4	14	5

Do you feel that the school is good at meeting your child's medical needs?					
Yes	59	45	19	123	46
No	4	3	9	16	6
Sometimes	16	9	15	40	15
Don't know	11	3	4	18	7
Missing	9	28	35	72	27
Do you think that the teachers understand enough about your child's strengths and needs to support your child appropriately?					
Yes	65	47	31	143	53
No	20	25	39	84	32
Missing	14	15	10	39	15

4. Discussion

The current study examined the educational provision and support for children with neurodevelopmental disorders that share overlapping phenotypes: children with WS and DS have similar overall cognitive functioning abilities and can be diagnosed from birth, whilst those with WS and ASD share behavioural difficulties but WS can be diagnosed earlier than ASD. In addition, overall WS is rare and less well-known by school staff compared to DS and ASD. Furthermore, parental satisfaction about the school placement settings and provision were compared across the different neurodevelopmental disorders.

The results showed that overall children move from mainstream to more specialist settings from primary to secondary school in all three groups. This finding is similar to previous studies in rare neurodevelopmental disorders and is likely to reflect the widening gap between typically developing peers and children with neurodevelopmental disorders and the increasing demands of the curriculum as children get older (Reilly et al., 2015). Yet, further analyses showed that, similar to previous studies, at primary school level children with DS were more likely to attend mainstream settings, in contrast to those with WS and

ASD (Cuckle, 1999; Fox, Farrell & Davis, 2004). The fact that children with WS are more likely to attend specialist settings is striking seeing that overall those with WS and DS have similar cognitive profiles and complex needs. One reason why children with DS might be more likely to attend mainstream settings compared to those with WS is that DS is more common. Thus, the needs of children with DS may be better understood compared to those with WS making it more likely that the needs of children with DS can be addressed in mainstream school. This may also explain why children with DS who are in mainstream primary schools receive more 1-to-1 support compared to those with WS who are in mainstream settings, in that the needs of children with WS, due to its rarity, may not be recognised as much. Very few studies have examined the educational needs of children with WS, either in the UK or in other countries (see Palikara, Ashworth, & Van Herwegen, under review for a discussion) and thus further research into how these needs can be addressed in the classroom in required. Another reason why the level of 1-to-1 support in mainstream settings differs between WS and DS, is that the abilities of children with WS may be overestimated and that they are perceived as being less in need of 1-to-1 support. Most children with WS are fluent speakers, despite their language comprehension difficulties, and their language competence contrasts to those with DS (Brock, 2007). Finally, it may be possible that only those with WS that have fewer complex needs attend mainstream school and thus they may require less 1-to-1 support. Still, the current findings for children with WS differ from those by Reilly and colleagues (2015) which suggested that WS in the UK receive more 1-to-1 support than other rare neurodevelopmental disorders. It is unlikely that this difference can be explained by any area specific differences in educational and service provision as the participants in the current study were recruited from across the UK. Rather, the results suggest that it is important not only to examine cross-syndrome comparisons of rare disorders but also of disorders that share the same cognitive and behavioural difficulties.

Children with ASD were least likely to attend specialist settings or to receive any 1-to-1 support, despite their behavioural difficulties and similarities with children with WS. This finding differs from Parsons et al (2009) who compared children with ASD with a mixed group of children who did not have ASD and found that there were no differences between those with ASD and non-ASD for type of educational setting and 1-to-1 provision. However, the study by Parsons et al (2009) did not specify the phenotypes of the non-ASD children included in their study and thus the type and severity of their needs is unclear. In the current study, however, those with WS and DS are more likely to have complex needs than those with ASD, despite the fact that there is wide variability in cognitive functioning in all three disorders (Charman, 2015; Tsao & Kindelberger, 2009; Van Herwegen et al., 2011) and that more children with ASD in the current study had an additional diagnosis. Again, this finding stresses the importance of including the appropriate control group when making conclusions about neurodevelopmental disorders.

A larger number of children with ASD were being home schooled compared to those with DS and WS. Many parents commented that this was caused by a lack of understanding by the school staff to appropriately support their child. This finding is similar to a previous study by Parsons and Lewis (2010) who also found in their survey that children with ASD were more likely to be educated at home, in contrast to children with other SEND and that for these parents the motivation to educate children at home included the fact that the school could not accommodate the child's specific needs. Seeing the similarities between the behavioural and sensory needs of children with WS and ASD, it is interesting to see that none of the children with WS were educated at home. Further studies are thus required to examine this difference.

Although there were no differences between the three groups for the proportion of children that received additional specialist support, it is important to note that only 62% of

the children receive any specialist help, despite the fact that all three neurodevelopmental disorders, and especially those with WS and DS, show delayed and atypical development across a range of abilities from infancy onwards (see Martens et al., 2008; Silverman, 2007 for a review). Similar to previous studies, including those outside the UK, (Fidler et al., 2002; Reilly et al., 2015), the type of support differed depending on the phenotype of the disorder. For example, despite the fact that language difficulties have been well reported in children with WS and ASD, children with WS and ASD are less likely to have access to SLT provision, in contrast to those with DS. However, the language difficulties in DS affect production as well we comprehension and are more salient compared to the language difficulties with comprehension and pragmatic use of language in WS and ASD. The total number of children receiving OT support was very small across all three groups. Few previous studies in the UK have directly examined access to OT support, especially in WS. However, previous studies have shown that parents of children with WS have often expressed a desire for more resources and support with regards to hand-writing/ fine motor skills, computer skills, as well as hygiene and care skills (Reilly et al., 2015). In addition, studies in the rest of the world have shown that OT access is limited, yet highly desired by parents, especially the implementation of OT support in the classroom (Fidler et al., 2002; Starr et al., 2006). Finally, support for children's mental health was also very limited across the three groups. This finding is in line with other studies that have examined mental health issues in children with SEN and have argued that atypical behaviours are often attributed to the child's neurodevelopmental disorders rather than recognised as a potential mental health symptom (see Rose, Howley, Fergusson & Jament, 2009 for a discussion).

Despite the fact that children with WS and ASD both have less access to 1-to-1 support and specialist support, the parents of children with ASD were most dissatisfied with the provision and support from the educational settings. Again, this finding is in stark

contrast with previous studies (Lindsay et al., 2016; Parsons et al., 2009) that showed there were no differences between ASD and those with language impairments or ASD and non-ASD for parental satisfaction with educational provision and specialist support. It is currently unclear as to why parents of children with ASD are less satisfied and further qualitative studies are required to explore this issue further. One potential explanation could be that due to budget cuts, children with ASD in mainstream school are receiving less specialist support. Previous studies have shown that the amount and type of specialist support in mainstream is linked to parental satisfaction for children with ASD (Lindsay et al., 2016).

Importantly, parents in all three groups mentioned that there are many issues about getting the right 1-to-1 support provision, with staff not being trained or specialist enough or lack of continuity of the person providing the 1-to-1 support. Dissatisfaction of parents with the lack of school personnel's knowledge about their child's disability is definitely not a new issue and has been discussed in studies in studies within and outside the UK as well (Lindsay et al., 2016; Starr et al., 2006).

In contrast to previous studies carried out both in the UK and other countries (Lindsay et al., 2016; Starr et al., 2006; Reilly et al., 2015), proportionally more parents of children with ASD did not think that teachers know enough about their child's strengths and needs to support them compared to the other two disorder groups, despite the fact that WS is rarer and that both developmental disorders show variable phenotypes. However, this finding might be influenced by the fact that children with WS and DS can be visually identified in contrast to those with ASD and that thus the needs of children with WS and DS are more quickly recognised. Alternatively, previous studies have shown that teachers have misconceptions about children with ASD and are more familiar with their behavioural difficulties than their strengths (Stone & Rosenbaum, 1988). This bias towards these difficulties might result in a lack of recognition of the child's strengths for children with ASD. In addition, more children

with WS were educated in specialist settings and teachers in specialist schools may be more aware of the fact that children in their setting have additional needs, in contrast to those in mainstream settings. These findings suggest that teachers overall should be made more aware of how they can support children with ASD in their classroom. Still, similarly to Lindsay et al. (2016), there were no differences between the three groups for the educational progress the children had made.

Although most parents viewed that the school could meet their child's physical and medical needs, for about a quarter of the children these needs are not consistently met and also a small proportion of parents did not know whether the needs of their child were met at all. This shows that more transparency is needed about the medical needs of children with SEN and how these needs can be met in the classroom. In 2014 a new code of practice was introduced in the UK which includes the introduction of Education, Health, and Care Plans (Department for Education & Department of Health, 2015). These EHCPs should include a better description of the child's medical and mental health needs, in addition to any educational needs, and provide parents with a better insight of how their child's needs will be met in the school.

One important limitation of the current study is that only data from parental reports was used and thus the data may not accurately reflect the practice within the school, especially when it comes to 1-to-1 provision and specialist support that the child is receiving in the school. In addition, parents were recruited via social media and parental organisations and thus it is possible that the results do not accurately reflect the views of the entire population of these neurodevelopmental disorders. However, there were group differences in satisfaction levels despite the fact that parents of children were all recruited in a similar way. If it were likely that a convenience sample only attracts those parents who are highly dissatisfied then parents of children with DS and ASD would be expected to be equally

dissatisfied. Still, even though the results cannot be representative of the entire populations, the current study highlights the views of some parents of children with WS, DS and ASD and provides important insight into how provision and satisfaction with this provision differs across the different neurodevelopmental disorders.

The current study only examined whether children have access to specific educational provision and support and whether parents of children with different neurodevelopmental disorders were satisfied with this provision and support. However, the current study did not examine how these factors are influenced by the particular severity of the disorder or where children sit on the spectrum. Therefore, the data in the current study should be followed up by interviews that can examine in further depth any reasons why parents are dissatisfied. Also, the current study examined some differences across the different school ages, mainly primary versus secondary school, using a cross-sectional sample. However, these results should be replicated using longitudinal samples.

4.1 Conclusions

It has been argued that specific education provision and support for different aetiologies would allow teachers and professionals to foresee any difficulties and adjust education provision to support improved educational outcomes for those with neurodevelopmental disorders. In order to examine whether or not education support and educational provision is syndrome specific, the current study examined parental views from three different neurodevelopmental disorders that share a number of overlapping features and difficulties. In contrast to previous studies, the current study found that the type of educational settings and support that children receive as well as parental satisfaction with education settings was syndrome specific. However, across all neurodevelopmental disorders access to specialist support remains low and the type of support children receive does not necessarily match the specific phenotypes that are involved. In addition, parents expressed

concerns about the lack of staff's training and knowledge with regards to their child's needs. Surprisingly, this satisfaction, although syndrome specific, was not related the rarity of the disorder. Therefore, the current study highlights areas for further improvement for SEND provision within the UK, especially to the knowledge of professionals with regards to the language and the socio-emotional difficulties children with ASD and WS experience and the limited access to specialist support that children with neurodevelopmental disorders have, especially to OT and mental health support. Finally, the number of empty answers and 'don't know' answers from parental reports, especially for 1-to-1 support and specialist support their child received, show that more communication is needed between the parents and the school staff about the type of support that their child is receiving. From a theoretical point of view the current study shows that selecting the correct control groups is important when examining educational provision and support in neurodevelopmental disorders, in that, previous studies did not find any group differences when WS was compared to other rare disorders (e.g., Reilly et al., 2015) or when individuals with ASD were compared to a mixed non-ASD group (e.g., Parsons et al., 2009). However, the current study shows that comparison of neurodevelopmental disorders that show overlapping and different phenotypes allows further insight into the specific and general difficulties that parents of children with SEND experience in relation to their child's educational provision.

5. Acknowledgements:

We would like to thank all the participants who took part in the research as well as the Williams Syndrome Foundation for funding this project.

6. References

Brock, J. (2007). Language abilities in Williams syndrome: A critical review. *Development and psychopathology, 19*(1), 97-127.

Charman, T. (2015). Variability in neurodevelopmental disorders: Evidence from Autism Spectrum Disorders. In: J. Van Herwegen & D. Riby (Eds.). *Neurodevelopmental disorders: research challenges and solutions*. London: Psychology Press.

Cuckle, P. (1999). Getting in and staying there: Children with Down syndrome in mainstream schools. *Down Syndrome Research and Practice, 6*(2), 95-99.

Department for Education and Department of Health (2015). *Special educational needs and disability code of practice: 0 to 25 years*. Available at: https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

Evans, D.W., Canavera, K., Kleinpeter, F.L., Maccubbin, E., & Taga, K. (2005). The fears, phobias and anxieties of children with autism spectrum disorders and down syndrome: comparisons with developmentally and chronologically age matched children. *Child Psychiatry & Human Development*, *36*(1), 3-26.

Fidler, D.J., Hodapp, R.M., & Dykens, E.M. (2002). Behavioural phenotypes and special education: Parent report for educational issues for children with Down syndrome, Prader-Willi Syndrome and Williams syndrome. *The Journal of Special Education, 36*(2), 80-88.

Fidler, D.J., Lawson, J.E., & Hodapp, R.M. (2003). What do parents want?: An analysis of education-related comments made by parents of children with different genetic syndromes. *Journal of Intellectual and Developmental Disabilities, 28*(2), 196-204.

Fox, S., Farrell, P., & Davis, P. (2004). Factors associated with the effective inclusion of primary-aged pupils with Down's syndrome. *British Journal of Special Education, 31*(4), 184-190.

Hodapp, R.M., Freeman, S.F., & Kasari, C.L. (1998). Parental educational preferences for students with mental retardation: Effects of etiology and current placement. *Education and Training in Mental Retardation and Developmental Disabilities, 33*(4), 342-349.

Leyfer, O.T., Woodruff-Borden, J., Klein-Tasman, B.P., Fricke, J.S., & Mervis, C.B. (2006). Prevalence of psychiatric disorders in 4 to 16-year-olds with Williams syndrome. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics, 141*(6), 615-622.

Lindsay, G., Ricketts, J., Peacey, L.V., Dockrell, J.E., & Charman, T. (2016). Meeting the educational and social needs of children with language impairment or autism spectrum disorder: the parents' perspectives. *International Journal of Language & Communication Disorders*, *51*(5), 495-507.

Martens, M.A., Wilson, S. J., & Reutens, D.C. (2008). Research Review: Williams syndrome: a critical review of the cognitive, behavioral, and neuroanatomical phenotype. *Journal of Child Psychology and Psychiatry*, *49*(6), 576-608.

Palikara, O., Ashworth, M., & Van Herwegen, J. (2018). Addressing the educational needs of children with Williams syndrome: a rather neglected area of research? *Journal of Autism and Developmental Disorders*. Advance online.

Parsons, S., & Lewis, A. (2010). The home-education of children with special needs or disabilities in the UK: views of parents from an online survey. *International Journal of Inclusive Education*, *14*(1), 67-86.

Parsons, S., Lewis, A., & Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: comparisons with parents of children with other disabilities from an online survey. *European Journal if Special Needs Education*, *24*(1), 37-58.

Reilly, C., Senior, J., & Mutagh, L. (2015). A comparative study of educational provision for children with neurogenetic syndromes: parent and teacher survey. *Journal of Intellectual Disability Research, 59*(12), 1094–1107.

Rodgers, J., Riby, D. M., Janes, E., Connolly, B. & McConachie, H. (2012). Anxiety and Repetitive Behaviours in Autism Spectrum Disorders and Williams syndrome: A Cross-syndrome Comparison. *Journal of Autism and Developmental Disorders, 42*(2), 175-180.

Rose, R., Howley, M., Fergusson, A., & Jament, J. (2009). Mental health and special educational needs: exploring a complex relationship. *British Journal of Special Education*, *36*(1), 3-8.

Silverman, W. (2007). Down syndrome: cognitive phenotype. *Developmental Disabilities Research Reviews*, *13*(3), 228-236.

Starr, E.M., Foy, J.B., Cramer, K.M., & Singh, H. (2006). How are schools doing? Parental perceptions of children with autism spectrum disorder, Down syndrome and learning disabilities: A comparative analysis. *Education and training in Developmental Disabilities, 41*(4), 315-332.

Stone, W. L., & Rosenbaum, J. L. (1988). A comparison of teacher and parent views of autism. Journal of Autism and Developmental Disorders, 18(3), 403-414. http://dx.doi.org/10.1007/BF02212195

Tsao, R., & Kindelberger, C. (2009). Variability of cognitive development in children with Down syndrome: Relevance of good reasons for using the cluster procedure. *Research in Developmental Disabilities, 30*(3), 426-432.

Van Herwegen, J., Rundblad, G., Davelaar, E.J. & Annaz, D. (2011). Variability and standardised test profiles in typically developing children and children with Williams syndrome. *British Journal of Developmental Psychology*, *29*(4), 883-894.